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ABSTRACT

This technical report is part of a series on AIDS/HIV (Acquired Immune Deficiency Syndrome/Human Immunodeficiency Virus) and is intended to help link various legal advocacy organizations providing services to persons with mental illness or developmental disabilities. This report discusses strategies to utilize existing disability models for provision of HIV legal advocacy services. The document considers: the need for coalitions of agencies to meet the AIDS public health crisis, legal advocacy service needs, and activities and services of Protection and Advocacy systems and Client Assistance programs. Examples are provided of programs serving persons with HIV infection including the Legal Center in Denver, Colorado, which has developed a comprehensive legal service system through building coalitions. Specific steps in building such coalitions are recommended to advocacy groups including: (1) locating members of the group/community and organizing; (2) identifying issues; (3) establishing goals, objectives, and timetables; (4) measuring success; (5) developing coalition leadership; (6) dealing with irrelevant or disruptive issues; (7) planning effective meetings; and (8) using the media. Contains 5 references. (DB)

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Building Coalitions to Provide HIV Legal Advocacy Services: Utilizing Existing Disability Models

David C. Harvey, M.S.W.
Robert S. Ardinger

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National Association of Protection & Advocacy Systems

The National Association of Protection & Advocacy Systems (NAPAS) is the membership organization of 86 Protection & Advocacy Systems (P&As) and Client Assistance Programs (CAPs) located in every State and U. S. territory. P&A agencies for persons with developmental disabilities (PADD) were created by Congress as part of the Developmental Disabilities Assistance and Bill of Rights Act of 1975 (P.L. 94-103). In 1986, Congress added the Protection & Advocacy System for Mental Ill Individuals (PAMII) (P.L. 99-319). The Client Assistance Program was created under Section 112 of the Rehabilitation Act of 1973 (P.L. 93-12).

P&As and CAPs are mandated to provide advocacy services through legal, administrative, and other appropriate remedies to protect the rights of persons with disabilities who reside in institutions, facilities, and other locations, and persons being served by state departments of vocational rehabilitation.

P&As and CAPs are increasingly confronting legal, policy and advocacy issues involving adults and infants infected with HIV, and a range of other issues associated with communicable disease policy, sexuality of persons with disabilities, and persons with dual diagnosis of mental illness or developmental disability and drug use. It is the hope of NAPAS that this series of technical reports will assist the field in responding to the newest challenge facing disability services.

Elizabeth W. Bauer
President, NAPAS (1990)
Executive Director, Michigan Protection & Advocacy Service, Inc.

Curtis L. Decker
Executive Director, NAPAS

Purpose of Publication

In 1988, NAPAS submitted a grant proposal to the AIDS Prevention & Service Program of the Robert Wood Johnson Foundation, Princeton, New Jersey, to develop AIDS legal advocacy services through technical assistance to NAPAS members and production of monographs and research articles. NAPAS was awarded a grant January 1, 1989 for one year, together with 54 other grant recipients nationwide.

Published in June 1990, this publication is the fifth in a series of technical reports on AIDS/HIV legal, policy and advocacy issues pertaining to mental health and developmental disability services. These technical reports are intended for wider distribution beyond Protection & Advocacy Systems and Client Assistance Programs to the disability and AIDS community, and are designed to help link various legal advocacy organizations in mutually beneficial and cooperative ventures. Although the responses and capabilities of agencies vary throughout the United States, these technical reports may provide assistance to others and can serve as guideposts for other organizations seeking to initiate or enhance similar efforts.

Comments and feedback on the usefulness of this technical report are welcome and should be addressed to David C. Harvey, Project Director, NAPAS, 220 Eye Street, NE, Suite 150, Washington, D.C. 20002, (202) 546-8202.

This technical report was written by NAPAS staff members David C. Harvey, M.S.W., and Robert S. Ardinger, M.A. A special thanks goes to Lynn Palma, Esq., of the Colorado Legal Center, for providing assistance in writing this paper. The author also wishes to thank the NAPAS AIDS Advisory Committee for assisting with the conception of this paper and review of initial drafts. The Committee consists of:

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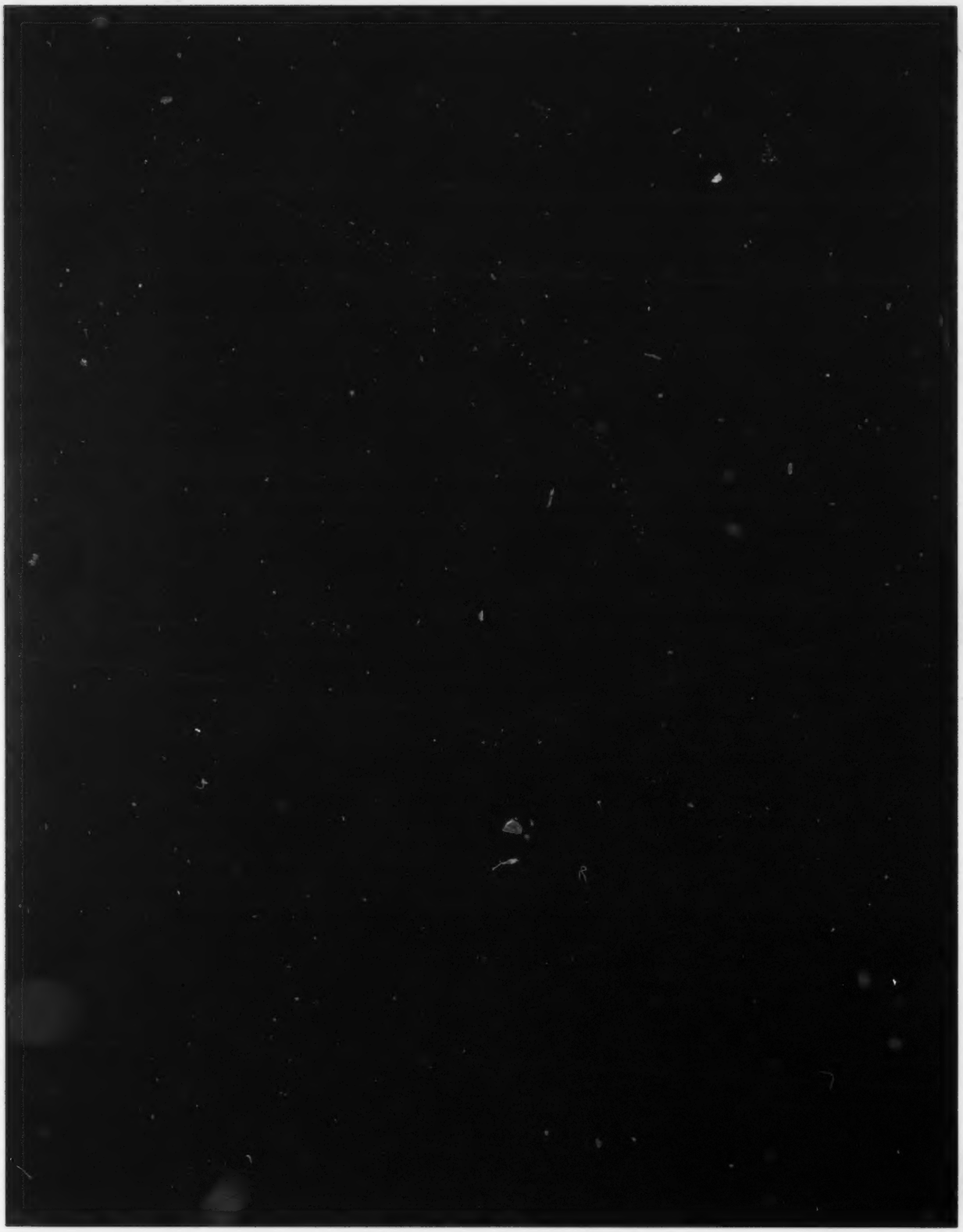

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Building Coalitions to Provide HIV Legal Advocacy Services: Utilizing Existing Disability Models

David C. Harvey, M.S.W.
Robert S. Ardinger

This monograph discusses the need to develop effective coalitions between groups who represent persons with Acquired Immune Deficiency Syndrome (AIDS), or what is increasingly called HIV disease, and other advocacy organizations. As of February 1990, 122,868 adults have been diagnosed with AIDS in the United States and U.S. Territories, according to the U. S. Centers for Disease Control (CDC) criteria for diagnosis. It is estimated that over 1.5 million people are infected with the Human Immunodeficiency Virus (HIV) and are asymptomatic carriers. HIV in advanced stages causes AIDS. By 1991, it is estimated that 270,000 persons will be diagnosed with AIDS. This figure alone threatens to overwhelm health and social service systems.

Adding to the implications of the above figures, as of February 1990 there were 2,116 children under the age of 13 diagnosed with AIDS according to CDC. The Public Health Service predicts 3,000 children with AIDS by 1992, with HIV infecting 20,000 children by that year. Of those 20,000, it is also predicted that 90% may mature with developmental disabilities. In addition, estimates also indicate that in the next five years, HIV may become the largest infectious cause of mental retardation in children under age thirteen. Predictions of HIV infection in other populations within the disability community, such as persons with mental illness who may be especially at risk for HIV are not available at this time.

AIDS is considered a "handicapping" condition protected under federal law and therefore will add to the already 36 million people in the United States with disabilities. In spite of this, HIV policy and prevention activities receive less focus within the disability population. Information from limited studies, and data from staff of the P&A system suggest that HIV policy guidelines are not well developed in institutional and community settings where persons with mental and physical disabilities are cared for or reside. This creates a compelling need for organizations which represent persons with AIDS, and organizations having longer standing who represent persons with other disabilities, to form coalitions to fill this void in public policy, education, and legal advocacy services.

As the demographics of the AIDS public health disaster continue to shift from primarily white gay men to other groups, issues of legal advocacy will play an increasingly important role in the activities of numerous organizations. Since AIDS is considered to be a handicapping condition protected under federal and/or state law, and because persons with disabilities may be at additional risk to exposure, there is a need to combine efforts to build coalitions that share information on strategies and approaches to advocacy programs.

AIDS and HIV disease threaten to overwhelm not only the health and social services systems, but also the legal advocacy systems which remains largely unprepared to handle increased numbers in cases loads. There are legal advocacy offices which are specifically geared toward AIDS related issues, such as legal service and ombudsman departments of community based AIDS service organizations (ASO's). However, other agencies that have traditionally handled legal advocacy for persons with disabilities are often limited in their resources and rely heavily on volunteer private bar lawyers to litigate on behalf of clients. In addition, some legal advocacy services which are part of ASO's may not be familiar with some of the more traditional disability policy and legal issues associated with persons who have chronic physical or mental disabilities.

Major efforts in the legal arena have been to assure that policies and approaches of private organizations concerning HIV are consistent with principles in a number of areas, primarily, access to the legal system and the administration of justice, confidentiality, public health law, access to health care, HIV testing and counseling, insurance, drug development, employment, discrimination, public school education, child welfare, family law, drug abuse, immigration, and education of the public. A Coordinating Committee of the American

Bar Association (ABA) has developed a set of policy recommendations to address these issues. The Committee notes, however, that although the ABA has adopted policies in some of these areas, there are still many significant legal issues which have not been addressed by the nation's lawyers and judges. The Coordinating Committee recommends that the ABA join with the many professional organizations which have already stepped forward to help educate their members and the public about HIV. Such joint efforts will enhance the development of policies and legal standards that increase the protection of the public health, while also securing adherence to the traditional rights and responsibilities recognized in a free society.

Organizations with AIDS/HIV legal advocacy experience, such as community based AIDS organizations, can provide significant direction to illustrate the kinds and range of services which similar organizations can pursue. To be fully effective, HIV legal advocacy agencies must be able to provide individual legal services such as wills, family planning, estates and entitlements, as well as internal dispute resolution services, training and litigation on rights issues both on an individual and on a systemic basis. In addition, technical assistance on policy issues and systems advocacy are further needs. Not all of these services should necessarily be provided by the same agency. However, the overall structure once established, should, as a totality, provide these services.

HIV and AIDS is the topic of much legislation at state and federal levels and impacting on this process is an important part of systems advocacy. The goals of systems change advocacy include: training consumers, service providers, and attorneys on current information on HIV legal issues, as well as the applicability of disability law to HIV. Individual case management services must include those needs related to the issues outlined above.

When viewing AIDS/HIV in the larger context of disability policy, many fundamental issues not new to the disability community emerge for re-evaluation. Concerns about HIV have highlighted existing issues involving infection control procedures and whether disability services adequately implement them, sexual behavior within facilities, confidentiality and possible duty to warn or protect, placement of clients in community settings and the least restrictive environment, and management of the non-compliant or recalcitrant client, and other issues. AIDS and HIV may prompt the disability field to re-examine certain prior inadequacies in these areas.

Increasingly, residential, habilitative, rehabilitative, child welfare and social services, health and education services designed to treat and care for persons with developmental disabilities will be forced to confront a new group of developmental disorders caused by infection with HIV. Persons entering developmental services with HIV, or the later stages of infection that results in a diagnosis of AIDS, will be of all ages that include infants who mature with developmental delay, to the adolescent or adult with developmental disability who acquires HIV through high-risk sexual activity or IV drug use.

Mental health services will be increasingly impacted by the adolescent or adult with chronic or severe mental illness who at times may have impaired judgement and because of possible accompanying high-risk behavior, may be at increased risk for HIV transmission. Mental health services include large state facilities, community mental health centers, rehabilitative and vocational day programs, and community residential services. Little is known about the etiological consequences of HIV infection in persons already diagnosed with mental illness, or about the interaction of drugs used to treat HIV and psychotropic medications.

A new area of concern is vocational rehabilitation issues for persons with HIV disease or AIDS. As persons with AIDS live longer and may experience diminished vocational skills, legal advocacy services can assist with obtaining different employment or skills training consistent with disability.

All of the issues mentioned above may be remedied through the provision of legal advocacy services. To date, some AIDS service organizations have provided their own legal advocacy services funded independently of government sources. Other legal service providers are constrained by mandates of Congress and funding levels, such as Legal Services Corporation, the Client Assistance Programs and the Protection & Advocacy Systems, and Long Term Care Ombudsmen Programs. Still other services are private non-profit agencies such as the American Civil Liberties Union, law school clinics, and other public interest providers. They are also constrained by available resources.

All of these providers have some common elements and can gain from the individual expertise and shared resources that can result from coalitions. One model of service provision is the P& A and CAP systems, which comprise the membership of NAPAS. A history of the statutory authority and activities of these providers is outlined below, and may serve as an example for other providers. In some cases, these agencies have specifically developed programs for persons with HIV disease and AIDS, or have assisted on cases through referrals to pro-bono attorneys collaborated on cases.

P&As and CAPs are increasingly confronted by legal, policy, and advocacy issues involving adults and infants infected with HIV, as well as other issues associated with communicable disease policy, such as sexuality of persons with disabilities and persons with dual diagnosis of either mental illness or developmental disability and drug use.

In 1975, Congress created the independent Protection and Advocacy System for persons with developmental disabilities (PADD) after conducting inquiries into rights violations concerning abuse and neglect in DD facilities. This system was established under the Developmental Disabilities Act of (42 U.S.C. 6001, et. seq.), which mandated that states provide advocacy services, including legal, administrative and other appropriate remedies, to protect individual rights.

Developmental disabilities are defined by the federal government as chronic and attributable to mental and/or physical conditions which appear prior to age 22. These disabilities must tend to be life-long and result in substantial limitations in three or more of seven major areas: self care; receptive and expressive language, learning, mobility, self-direction, the capacity for independent living and/or economic self-sufficiency. Many infants and children with HIV infection mature with developmental disability that meets this federal criteria. These children are eligible for a wide array of federal and state supported services for children and developmental disabilities.

Section 112(a) of the Rehabilitation Act of 1973, as amended by the Rehabilitation Act Amendments of 1984 (29 U.S.C. 732), mandated the establishment of Client Assistance Programs (CAP), reflecting the belief of Congress that persons with disabilities require assistance in obtaining information on access to services provided under the Act. The purpose of CAP is to advise vocational rehabilitation clients and client applicants about all available services under the Act; to assist them in their relationships with projects, programs, and facilities providing rehabilitation services (DVR) under the Act; and to assist in this process through the use of legal, administrative and other appropriate remedies to ensure the protection of rights. As mentioned previously, persons with HIV disease may have the need for vocational rehabilitation services. CAPs may be able to provide assistance in this area.

In 1986, the Protection and Advocacy for Mentally Ill Individuals Act (commonly referred to as PAMII) was passed (42 U.S.C. 10801, et. seq.). This Act was modeled after the PADD, and established a system that protects the rights of persons with mental illness under federal and state statutes. The individuals covered under the Act must (1) reside in facilities which provide 24 hour care and treatment; (2) have been discharged from such a facility within the past 90 days; (3) are being transported to 24 hour care facilities; and (4) under certain situations involve prisons and jails.

All P&A staff consist of attorneys, social workers and other advocates who are capable of providing a full range of advocacy services including the ability to pursue legal, administrative and other appropriate remedies to protect the rights of clients. The programs must be independent of any service provider to assure conflict-free advocacy services. The Governor of each state designates the program to fulfill the P&A mandate and cannot redesignate the program without good cause. Each program within the P&A system for persons with mental illness has an advisory board consisting of consumers, families, attorneys and other advocates.

P&A and CAP activities include: (1) investigating, negotiating or mediating solutions to problems expressed by persons with developmental disabilities, persons with mental illness or clients of DVR's, their families or agency representatives; (2) providing technical assistance to attorneys, governmental agencies and service providers; (3) providing legal counsel and litigation services to persons in these populations and groups who are unable to attain adequate or appropriate legal services in their communities; and (4) training advocates, consumers, volunteers, professionals, and other interested persons.

The P&A systems work with institutions, including residential care givers, public and private hospitals for persons with mental illness or mental retardation, vocational rehabilitation agencies, public schools and state correctional facilities in addition to a host of other service provider and governmental offices. The P&A systems also provide advice and technical assistance to attorneys on issues such as disability and mental health law as well as providing assistance to various boards, commissions and government officials.

P&As report a high percentage of successful resolution of clients' problems through means other than full litigation, with less than 5% of the national caseload involving litigation. These efforts include advocacy, mediation, and negotiation.

Protection & Advocacy Systems and Client Assistance Programs to varying degrees have handled individual clients with HIV and systemic legal and policy issues regarding HIV infection. During the fall of 1989, NAPAS conducted an AIDS needs assessment through a detailed survey. Many state Systems have handled individual cases involving HIV services within mental health institutions and developmental disability services, with specific issues involving medical and social services, entitlements and finances, housing, nursing care, rights issues such as visitation rights, informed consent, confidentiality, and other issues.

Several P&As and CAPs have worked closely with state American Civil Liberties Union, legal services corporation, community based AIDS organizations, state AIDS/HIV Coordinators, state Alliances for the Mentally Ill, and state Associations for Retarded Citizens. Some P&A and CAP agencies are unrestricted in who they may serve because of outside funding sources other than the federal government, which requires service be provided only to clients that have diagnosis of mental illness or developmental disability. This has allowed some P&A and CAP agencies to be extensively involved in HIV issues.

For example, Alaska P&A worked with two children with hemophilia who subsequently contracted HIV and needed assistance with access to special education classes. California P&A was involved with clients in mental health institutions who were involuntarily tested for HIV without informed consent. Connecticut P&A to date has handled twelve cases involving exclusion for school based on HIV status, termination from a group home for persons with mental illness because of HIV status, and a woman with AIDS and her three children who were homeless.

The District of Columbia P&A represented an adolescent who tested HIV positive and was held inappropriately at St. Elizabeth's Hospital for lack of a suitable residential placement. In addition to forcing the D.C. Department of Social Services to fund an appropriate foster care placement, D.C. P&A filed a federal damage action and is demanding that an appropriate citywide policy be developed.

Florida P&A provided extensive legal research and writing on behalf of the plaintiff's attorney in *School Board of Nassau County v. Gene H. Arline*, heard before the Supreme Court in March of 1987. The Court decided that a medical condition caused by an airborne infectious agent (tuberculosis), could be considered a handicap under Section 504 of the Rehabilitation Act, which was held to include HIV infection.

Louisiana P&A represented a nurse who was fired for her job for failure to disclose an HIV antibody test. A second case involved a young man who was terminated from his job after testing positive for HIV.

Other P&As and CAPs have been integrally involved with policy development and systemic issues in mental health, developmental disability, vocational rehabilitation, and other medical and social service systems. Many P&As and CAPs have been involved with legislative advocacy activities in the areas of antidiscrimination, confidentiality, and public health measures.

The Legal Center: Denver, Colorado

The Legal Center in Denver, the designated P&A, CAP, and Long Term Care Ombudsmens program for the state of Colorado, has undertaken a number of individual employment and housing cases involving persons with AIDS. This was at the direction of its Board of Directors who decided that an outreach plan needed to be developed and implemented for persons with AIDS.

The Legal Center has had more freedom to provide these services than other agencies because of outside fundraising activities and joint collaboration with local AIDS service organizations. This agency probably more than any other in the country, has had the resources to provide extensive services to persons with AIDS or HIV infection. Examples for the Legal Center's activities include the following.

Lynn Palma, Esq., attorney for the Legal Center, successfully litigated a temporary restraining order under the Employee Retirement Income Security Act (ERISA). This was the first case of its kind in the country involving AIDS discrimination. United States District Court Judge Lewis T. Babcock ordered the employer to assume responsibility for the former employee's medical costs and shortly thereafter the case was settled.

In a number of administrative forums, the Legal Center has successfully represented persons with AIDS, persons with HIV infection, and persons who were significant others or lovers of persons with HIV infection. The Center represented a person before the Office of Civil Rights, department of Health and Human Services and settled the case after OCR entered a finding of discrimination, the first employment discrimination case involving AIDS for that federal region of the country. The employer was a group home providing services to persons with developmental disabilities.

The Legal Center has also identified a number of areas where AIDS affects the service systems used by other Legal Center clients that include the following:

- Special education classes and access for children with HIV.
- Adults with developmental disabilities and HIV infection and access to services, housing, and education.
- Individuals with mental illness who have similar needs as adults with developmental disabilities, as well as persons with HIV related mental disorders who present special issues for service providers.
- Public disability benefits and entitlements which the Center has expertise with and where the AIDS community expressed interest in obtaining more information.
- Vocational rehabilitation for persons with AIDS. For example, an architect wanted assistance in obtaining a real estate license which afforded him a more flexible schedule in order to manage his illness.
- Long term care where persons with AIDS share the experience of persons with other disabilities in obtaining appropriate housing while requiring less skilled care than nursing homes.

The Legal Center developed an AIDS Legal Fund with support from the gay community, AIDS service organizations, and other legal service providers and through various fundraising activities. Through June of 1989, the Center represented 35 clients with AIDS which involved costly litigation in a number of cases. Funded solely through private funds, the costs of services increased in 1989 from $61,872 to $95,581.

Through efforts to build coalitions the Center developed a comprehensive legal service system through a private pro-bono attorney referral system and co-counsel mechanism. Each Wednesday, the Colorado AIDS Project and pro-bono attorneys provide services in the area of wills, living wills, and power of attorneys. Legal Aid represents persons with AIDS in bankruptcy matters. The ACLU is examining HIV issues in prisons. The Lawyers Committee for Civil Rights in Colorado has assisted in education programs. The Legal Center is the only organization currently handling complex test cases in Colorado. Referral agreements were established between all organizations.

Other Funding Strategies

In addition to the examples provided above, other legal advocacy services should consult private and public sources of funding to provide services for persons with HIV. Although the federal government has provided little or no money for HIV legal advocacy services, legislation currently under consideration by Congress may allow small amounts of funding.

The Comprehensive AIDS Resources Emergency Act now before Congress, designates emergency funds for areas of the country hardest hit by this public health disaster, in the form of funding for consortiums of care. Included within this consortium is legal services. At the time of this printing, the bill passed the Senate (May, 1990), and is now being introduced in the U.S. House of Representatives.

Other sources to consult include:

National AIDS Network
2033 M Street, NW
Washington, DC 20005 (202) 293-2437

AIDS Information Clearinghouse
P.O. Box 6003
Rockville, MD 20850 (800) 458-5231

National Lawyers Guild AIDS Network
558 Capp Street
San Francisco, CA 94110 (415) 824-8884

Building Coalitions

This section contains suggestions for those organizations seeking to build coalitions with local legal service providers and AIDS service organizations. Although these suggestions are simple and basic, they can serve to remind persons in the field why coalitions are important and how to go about forming these associations.

Definition

For the purpose of this monograph coalition will be defined as a voluntary union of individuals, groups, organizations, or states which is formed to pursue a common objective or goal. The late 1960's and early 1970's saw a joining of persons with disabilities and advocates of all types in support of major pieces of Federal disability related legislation. A notable example is the massive coalition effort in 1977 by organizations and individuals representing disabled people and other groups, to persuade the former Department of Health, Education and Welfare to promulgate regulations to implement Section 504. This voluntary collaboration of a diverse range of groups to effect legislative change represents an ideal sense of coalition building. It is an example of how organizations who have a very unique and separate set of interests and goals can join together to combine resources and focus on those common, often more elusive interests which, once realized, pave the way for greater gains in an individual group's agenda.

Why Coalition Building is Important

As the example above points out, coalition building is important because it provides a powerful means for individual groups and organizations to combine their various resources and skills to address a pressing common goal or need to effect change through collective power—changes that might not be possible if approached in a fragmented manner. The successful coalition efforts of disability organizations in the 1960's and 1970's came about through the realization that the inequities which people with disabilities were experiencing were also civil rights issues. Borrowing from lessons learned by the civil rights movement, organizations representing various disabilities joined together to focus on broader economic and social issues common to all persons with disabilities, and thus bring a more unified message to Congress and the Federal Government about the needs of persons with disabilities.

Coalition building between groups representing persons with HIV disease and other advocacy organizations, is of particular importance in view of the limited amount of resources available, and the overwhelming human and personal tolls involved with HIV infection and its consequences. Persons with HIV disease risk the loss of their livelihood, their homes, and access to essential health care and community services, while also facing various forms of discrimination and social stigma. There is already recognition, within the context of the Americans with Disabilities Act (ADA) now before Congress, that persons with HIV disease need the protection of broad Federal anti-discrimination legislation. Increased availability of HIV legal advocacy services would both help with the urgent systemic policy needs, as well as address individual legal needs. For many states and communities and because of limited resources, the most effective way to assure provision of such essential legal advocacy services may be through coalition efforts.

Steps in Building a Coalition: Suggestions for Advocates

An important first step in forming a coalition is the need to recognize that coalitions can exist even if there are differences among the individual groups or persons who make up the coalition. It is not essential to agree on everything. What is important is to recognize the larger and more common issues, and have a willingness to work together in an environment promoting mutual agreement, flexibility, patience, and team work.

Coalitions provide a means for increased resources, greater visibility, political power and leverage, and a broader base from which to exercise that power. Coalitions can promote learning and provide a forum for gaining hands-on knowledge and experience through information sharing and "think tank" activities. Coalitions can save already scarce dollars by providing for an opportunity to share space, staff, facilities, equipment, and other resources. Finally coalitions can promote increased understanding of the goals and needs of the various groups making up the coalition, which can have the effect of dispelling past misunderstanding or perceived differences which may have prevented the groups from working together on other issues.

Organizations interested in forming coalitions to promote the provision of legal advocacy services for persons with HIV disease are encouraged to formulate a plan that is built upon currently existing organizations in the target geographical area. The following steps and strategies will provide a good starting point.

A. Locating Members of the Group/Community Organizing

A good place to start the formation of a coalition is to study the community's existing organizational structure to identify groups, organizations, or individuals having similar interests or needs. One of the areas covered in the AIDS Needs Assessment Survey of 32 state agencies (discussed previously) was the extent that collaborative efforts were utilized by a number of the agencies. The results showed that collaboration with organizations such as the American Civil Liberties Union; State AIDS/HIV task forces; community based AIDS organizations; legal service corporations; state organizations serving the mentally ill, and state associations serving other persons with disabilities such as persons with mental retardation can be an effective method of gaining information and sharing resources.

As you consider organizations, give careful thought to how the coalition will be able to benefit all groups involved. In addition, give some thought to the way you envision the coalition in action. Do you want only an increased power base to influence legislators? Do you want the coalition to be a permanent organization or more of an ad hoc working group? Will the organizations you have in mind have a compelling enough need to join the coalition. If not, can you exercise sufficient persuasion to show them that there is such a need or benefit to them? The next step in this process would be to look at the organizational structure on a larger scale—state-wide, regional and national. This will give you an idea of what organizations and individuals may be able to contribute to the coalition from a larger framework. On a state-wide basis, for example, competition for funds may make it useful to enlist the participation of organizations that would also be likely to be searching for funding for activities similar

to the kind you wish to fund, such as legal services. In this regard, the funding requests might be broadened and made stronger by showing a larger population having unmet needs who could benefit from the service.

B. Identifying Issues

Identifying issues begins at the point of where the group feels that something is wrong. It is helpful to think of such issues in broad terms or even as goals; these broad terms or goals can then be broken down to identify problems at a system level.

Issues can be identified as a result of an individual problem, particularly if they are specifically community issues, e.g. someone who can't find a place to live may be raising the issue of the larger problem of the lack of affordable housing.

Issues can also be identified by a group. Having access to medication or having the right to refuse a particular medical treatment has had a long legal history in the mental health advocacy arena. This issue has impacted the question of treatment and persons with HIV infection. When do persons with HIV disease have the right to access certain types of medication which may not have already been approved by the Federal Drug Administration? What legal advocacy services need to be created or what client referral procedures need to be established between service providers to effectively intervene with this problem?

Carefully defining the problem or issue to the group helps to keep the group focused on the task at hand and eases feelings of mistrust that may develop. Avoid adhering to your own programs so rigidly that you cannot work on a common agenda. This does not mean you have to surrender any position your own organization feels about strongly. Those issues can remain as part of your individual organization or group. Defining issues will help lead to finding the "common ground" for the members of the group.

C. Establishing Goals, Objectives and Timetables

A goal is a statement about the solution or part of the solution to the issues (problems) identified. Ideally, the goal is the desired end result of efforts made to address the problem. The success of the coalition will depend largely on the groups ability to recognize their mutual interest, by focusing it in terms of a common goal and in ways of arriving at a solution. For example, the civil rights movements for blacks, women, minorities, and persons with disabilities have created successful coalition efforts by recognizing such common goals as the realization of the right of all individuals to be given equal opportunity in Federally funded programs and services. Goal setting is the identification of the specific points or objectives which the group wishes to attain after completion of the project.

Setting up the specific steps you need to take to accomplish your goal is the establishment of objectives. For example, if one of your issues is the lack of readily available information for persons being impacted by HIV disease, and your goal is to develop a handbook or resource book to address this need, you need to set objectives and their related activities. For example, you will need to identify resources (the objective) by surveying the community services available, getting service programs to give you a description of their services and criteria, etc. (the activities). Other objectives will be to decide what type of handbook you want to print, and then plan ways to distribute the handbook, etc. By breaking down your goal into step-by-step objectives you will gain a clear picture of what you want to accomplish. Further breaking down your objectives into scheduled activities will give you a better understanding of what you will need to do to accomplish those objectives.

The time necessary to complete tasks begins with a realistic estimate of how much time it will take to complete each objective. You will need to think about scheduling the work of the project so that there is time to get each objective completed, and when it's time to move on. It may be difficult to be exact, but through your current knowledge, you will have an idea of how quickly your organization can move.

D. Measuring Success

The establishment of a coalition is the result of a gradual and often uneven process. An effort may succeed in part, then falter, and then pick up again and go on. Since mutual trust is built up over a period of time, coalitions should avoid getting so caught up in any one effort as to view it as "make or break." Every effort at cooperation among groups prepares the way for greater and more sustained efforts in the future. As organizers develop relationships with groups and work together, they gain the experience necessary to cope with matters that require a greater degree of trust and cooperation.

E. Coalition Leadership

A coalition leader has to play many roles: organizer, teacher, politician, negotiator and visionary. Functioning in these roles calls for effective personal skills, all of which determine the difference between an effective and in-effective leader. These roles

require good communication, interpersonal, and organizational skills.

Organizational skill begins with the leader's ability to be a skilled and active listener. This means eliciting recommendations from every member of the group and formulating them into an overall policy upon which the group can agree. Circumventing the process and making decisions without consultation may sometimes bring quick results, but will be counter-productive of the coalition's long-term unity and effectiveness.

F. Dealing with Irrelevant or Disruptive Issues

Begin by understanding the difference between those who have comments which are stimulating and thought provoking and those individuals who simply inject irrelevant comments or rhetoric. What might appear to be disruption may play a constructive role with the group by forcing a concentration on the main issue.

A leader can minimize potential disruptive diversion by establishing ground rules for meetings. For example, a leader of one coalition meeting had requested that one member speak at a time, due to the fact that one of the members of the group was hearing-impaired and required an interpreter for the meeting. This rule was necessary because it is impossible for an interpreter to interpret when more than one person is talking. This rule also had a positive effect on an individual who was argumentative.

G. Effective Meeting Planning

Coalitions can use meetings as an effective means of conducting and carrying out various aspect of the group's goals, objectives and activities. In this regard, it is important to ensure that meetings are productive and make the best possible use of the time of all individuals involved.

Some of the coalition's early meetings will need to focus on those areas discussed above—identifying issues, goal setting, breaking down goals into objectives and activities. Once this essential work has been done, an important next step will be to establish priorities among those issues identified. The group will need to be flexible in reaching a consensus on which issues to pursue first, second or simultaneously. When considering taking on several important issues at once, be sure the result will not be an overload of responsibilities on coalition members, particularly if most members will still be pursuing their own organization's agenda. If coalition members take on too much too soon the overload could result in a serious faltering of the coalition effort.

Once the coalition has its goals well defined and a carefully planned strategy in place for addressing issues, meetings will provide the opportunity to report on and review progress, make decisions about any needed changes in strategic plans, share information and ideas, provide opportunities for brainstorming, provide support and encouragement, and keep up active interest and enthusiasm for the coalition's goals.

The coalition leadership should take some steps to ensure that meetings are well planned and run smoothly. An essential tool is the meeting agenda. The agenda should be short, but specific enough to clearly lay out what the purpose of the meeting is, and what will be discussed. Don't list every possible issue with the idea in mind that there will be sufficient time to discuss everything. Do include on the agenda those items having highest priority, and build into the agenda sufficient time for discussing accomplishment of objectives in terms of projects or specific activities. Be sure to set time tables, identify resources or otherwise assign responsibilities so that members will know who is responsible for what, and make some decisions about how much you want accomplished between meetings or by a certain date. An effective leader will want to have some pre-thought-out ideas about these items in order to be able to give the group alternatives to consider. This will help keep things moving along.

Another good way to ensure that meetings stay on the agenda and progress without needless delay will be to provide a copy of the agenda to the members in advance of the meeting. In addition, send the members copies of any printed materials they will need to read or consider before the meeting. If individual members have specific areas to discuss, ask them to provide a copy of any materials, or an outline of their presentation, for advance distribution to the members.

H. Using the Media; Coalition Communications

The media can be an effective tool in getting a coalition formed and recognized. Coalitions need visibility in order to carry out many of the important functions of the coalition. For example, if one of the goals of the coalition is to increase public awareness about HIV disease, then a public awareness program will serve as an integral part of the coalition's overall activities. The media can also provide needed focus and attention on problems—on those critical needs that have caused an individual or a group to make the effort to form a coalition.

One of the coalition's first steps should be to develop a flyer or brochure about the coalition—its purpose, goals, planned activities, services (if any), location, and so forth. Such a flyer can also be used to serve as an invitational tool to invite other organizations or individuals to join and/or support the coalition. The coalition may also want to develop policy or position papers on certain issues. These statements will serve to clearly set forth the coalition's position with respect to a given issue; what the coalition believes should be done and how it can be accomplished. These position papers can also be a vehicle for supporting needed fundraising activities.

One of the most crucial aspects of a coalition's success will be the success of its internal and external communications. The coalition will, through effective and carefully nurtured internal communications, provide the means for enlisting and retaining members, keeping the coalition active and informed, and resolving conflicts which might threaten the coalition's existence. In addition to good communications during meetings, coalitions should consider developing a regular newsletter to keep members informed of issues, progress, activities, and other functions. The newsletter can be targeted primarily to coalition members, or it can also be used to communicate with the community at large about the goals and activities of the group. The newsletter can also help with fundraising by serving as a "record" of the coalition's efforts, activities and accomplishments. Finally, the newsletter can be used to recognize contributions of individual or organizational members. Giving people credit and encouragement for work well done is an excellent way to keep people interested and motivated.

Newspapers can be an effective means of securing public attention and/or support to one or many of the coalition's common goals. This can be accomplished both by the use of ads and by more detailed coverage, such as human interest stories, or coverage of a specific event, such as a major conference. Television and radio are another effective means of gaining visibility for the coalition or focusing public attention on a particularly critical problem.

Finally, use of conferences can be an effective means for providing both visibility for the coalition and its goals, and for providing a forum for developing strategies, enlisting new members and community involvement, raising funds, and effecting or involving legislative officials. The coalition can either plan its own conferences or arrange to have coverage of coalition issues during conferences held by other organizations.

The above discussion has served as an introduction to strategies in forming coalitions between service providers and other organizations to provide or create legal and advocacy services, to confront the particular legal and policy problems associated with mental health and developmental disability services, and to organize for political purposes to win additional resources and remedy certain issues.

As the demographics of the AIDS/HIV public health disaster change, so will the need to be more creative as solutions are sought for complex legal and policy issues associated with this disabling disease. Increasingly, service providers and program planners are challenged to reach people living within the inner cities, persons of color or different culture, and persons who lack access to health care, insurance, educational systems, and other providers. Building coalitions is an important area towards meeting these challenges. Coalitions can help further the development of public policy and human services which are aimed at meeting the needs and enhancing the lives of persons affected by HIV.

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